

Sharing Public Health Information for Data Integration Activities

Data Stewardship Policy and Data Sharing Agreement

**Child Health Advanced Records Management (CHARM)
Utah Department of Health**

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All Kids Count, a program of The Robert Wood Johnson Foundation.

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Foreword

This report is supplemental to the Final Report for the Utah Department of Health (UDOH) under its contractual agreement with All Kids Count (AKC), Center for Innovation in Health Information Systems, a program of The Robert Wood Johnson Foundation. As part of the agreement, the UDOH committed to provide a Data Sharing Agreement as part of the body of knowledge for health systems data integration. This report has been designed as a standalone document.

To assure subject matter expertise for each contract deliverable, the UDOH assigned a point person for each deliverable. In addition, a schedule for deliverable completion was developed and was used for progress tracking.

With approval from AKC prior to the end of the grant period, the Data Sharing Agreements deliverable was modified. It was agreed that a draft Data Stewardship Policy would be included as a deliverable with a Data Sharing Agreement as a policy attachment.

Connections is an AKC initiative created to advance the concept, implementation, and practice of integrated preventive health information systems. The UDOH is committed to sharing its draft Data Stewardship Policy and Intra-Agency CHARM Data Sharing Agreement with its fellow *Connections* Collaboration partners.

Executive Summary

Project Description:

The Utah Department of Health (UDOH) drafted a data stewardship policy for intra-agency program-to-program data sharing and desires to communicate this sample policy as part of the body of knowledge with others interested in health systems data integration.

Approach:

Rather than developing individual formal data sharing agreements between each participating program, the UDOH decided to formalize a policy on data stewardship. A draft data stewardship policy was developed with a data sharing agreement as a policy attachment. The draft Data Stewardship Policy was reviewed by the UDOH Information Systems Steering Committee (ISSC), Legal Counsel, and the Operations Steering Committee (OPSCOM). It was approved and adopted by the Executive Management Team (EMT) on March 3, 2003.

Conclusion:

Both the health systems data integration project team members and the participating program staff agreed that individual program-to-program agreements would be too onerous and time consuming to develop, manage, and maintain. For the purpose of data sharing among programs within an agency, an overall agency data stewardship policy was felt to be more helpful and appropriate. Within the policy, programs are encouraged to develop data sharing agreements for tracking and for clarifying appropriate uses of data.

Next Steps/Recommendations:

Upon this final Executive approval, the Policy will be communicated to the Department as a whole. Work will begin on finalizing the Data Sharing Agreement (Appendix B).

Overview

Historically, the Utah Department of Health (UDOH) public health information system has been very de-centralized, resulting in duplicate demographic information across programs, and non-existent, or inefficient mechanisms for sharing pertinent data between programs. The UDOH desires an integrated public health data system to permit the sharing of data among Department programs. Programs desire to maintain their own program data and control what data is shared and with whom.

The principal public health data integration effort of the UDOH is referred to as the Child Health Advanced Records Management (CHARM) project. The primary goal of CHARM is to create a virtual health-care profile for every child in the State of Utah and to allow real-time data sharing across multiple UDOH programs. Integrating various UDOH databases will provide for immediate access to information that is stored in specific databases to track and monitor screening results, immunization status, referrals, assessment, treatment, and outcomes for children and their families. The integrated system will reduce redundant data entry, increase accountability, and decrease the fragmentation of data and health care services. It is believed that CHARM will be a rich source of integrated data to store in a data warehouse that will serve as a repository for historical and statistical data and will allow for longitudinal studies, analysis, research, reporting, and policy development.

In working with UDOH programs to develop data sharing agreements, both the programs and the project team felt that individual program-to-program agreements would be too onerous and time consuming to develop, manage, and maintain. Additionally it was felt individual agreements would be largely pointless for anything other than documentation. Since the initial release of the CHARM data integration project will only consider data sharing between programs internal to the Department, a simpler approach was proposed.

In lieu of individual data sharing agreements, the UDOH decided to formalize a policy on data stewardship. Upon adoption of this policy, CHARM would no longer be required to develop Data Sharing Agreements for programs to share internal data within the Department. However, it should be noted that within the Policy, programs are encouraged to develop data sharing agreements for tracking and for clarifying appropriate uses of data.

The Data Stewardship Policy was drafted to:

- assure data is treated as an asset and is utilized to the fullest extent
- assure wide and appropriate access to and use of data
- assure coordinated collection of data and requests for data
- provide guidance for data sharing practices
- assure appropriate management of data to protect confidentiality and integrity

- clarify appropriate roles and responsibilities associated with the implementation of the policy.

The Intra-Agency CHARM Data Sharing Agreement was drafted for the UDOH through the efforts of multiple stakeholders. Face-to-face interviews were conducted by two Information Analysts with each program targeted for the first phase of integration under CHARM. One of the objectives of the interview was to gather information relevant to the development of Data Sharing Agreements.

As a general consensus, it was felt that a Data Sharing Agreement needed to contain the following information, at a minimum:

- data provider
- data requester
- purpose of the request
- justification for access
- description of data
- assurance of confidentiality
- period of agreement
- appropriate signatures

In some cases it was felt that an agreement might also include other information, such as:

- data users: (everyone in the program who uses the data)
- data use intentions
- method of access or transfer
- method and location of data storage and custodial responsibility
- data-sharing project costs
- criteria met for data sharing by program
- disposition of data

For the documentation in Appendix B, the agreement developed through the Office of Vital Records and Statistics (OVRs) is used as an example. The Confidentiality Pledge (Attachment A) contained within the OVRs Data Sharing Agreement utilizes the UDOH Utah Health Data Committee of the Office Of Health Care Statistics rather than one from OVRs.

Utah Department of Health

Data Stewardship Policy

I. Purpose of Policy:

- A. Assure data are treated as an asset and utilized to the fullest extent;
- B. Assure wide access to and use of data within the limits of existing statutes, rules, federal requirements, Department policies, and relevant ethical principals;
- C. Assure coordinated collection of data and requests for data;
- D. Provide guidance for data sharing practices;
- E. Assure that data are managed to protect confidentiality;
- F. Assure that the data are used in the proper context;
- G. Establish roles and responsibilities associated with the implementation of this policy.

II. Background:

Data are essential to the mission and purpose of the Utah Department of Health (Department). Data collected by organizational units or individuals within the Department are collected under the authority of the Department. The stewardship and use of those data are ultimately the responsibility of the Department. All Department employees and contracted individuals working for an organizational unit within the Department must protect the confidentiality of the data and are subject to the Department Confidentiality Policy.

The missions and purposes of organizational units within the Department often complement each other and sharing data helps the Department to accomplish its overall mission. In order to help the programs meet their goals, the Department supports data sharing between its organizational units whenever that sharing supports legitimate public health purposes.

Organizational units and their data stewards are responsible to ensure the best and proper use of data under their stewardship. They should facilitate and promote the sharing of data as an asset to support legitimate public health purposes. Comprehensive data sharing agreements are generally needed when sharing data with parties outside the Department. For data sharing within the Department, written policies, protocols, and agreements are encouraged for tracking purposes and for clarifying appropriate uses of data.

Data stewards may limit access to data resources when necessary to exercise appropriate stewardship of those data (e.g., preventing inappropriate disclosure of confidential data). However, the exercise of data stewardship includes the support of internal data sharing and does not include arbitrarily restricting access to data resources.

III. Policy

A. Responsibilities:

1. **General Employee Responsibilities** - All individuals in the Department who use health data have general data stewardship responsibilities. The general data stewardship responsibilities include:

- a. Protecting the confidentiality of identifiable health data by disclosing individually identifiable information only as allowed by this policy, other Department policy, or state or federal law;
 - b. Treating the Department's health data as a Department-wide asset;
 - c. Using the Department Data Inventory published on DOHnet, the Department's Intranet, or using the Department's Analytic Network Coordinating Team (ANCT) to verify that needed data do not already exist before engaging in collecting data;
 - d. Using Department data resources within the limits set by statutes, rules, federal requirements, Department policies, and relevant ethical principles; and
 - e. Facilitating appropriate use and sharing of health data in support of the mission of the Department, within the limits set by statutes, rules, federal requirements, Department policies, and relevant ethical principles.
2. **Division Responsibilities** - Each Division/Office Director whose organizational units/programs collect or hold health data is responsible to:
- a. Determine which of its data resources are significant sources of information for disease and risk factor surveillance, needs assessment, policy making, and program evaluation;
 - b. Assign a data steward for each significant data resource under their management;
 - c. Publish (in the Department's Data Inventory on DOHnet) their names and contact information along with their assigned data resource inventory;
 - d. Include data stewards' assignments and responsibilities in the performance plans for named individuals;
 - e. Advise the data stewards under their supervision when data stewards bring issues to their attention for resolution;
 - f. Seek to include data sharing provisions in all federal or private grants and contracts entered into on behalf of the Department;
 - g. Seek resolution within the Department's chain of command for issues related to data use and data sharing; and
 - h. Assure that Institutional Review Board (IRB) or ethics committee human subjects review are obtained where appropriate.
3. **Director of Center for Health Data Responsibilities** – To bring consistency in data stewardship performance, the Director of Center for Health Data will directly conduct regular audits to review data sharing requests and their resolution and provide guidance to the appropriate data stewards or delegate the audits to an individual or to the ANCT.
4. **IRB Responsibilities** – refer to the IRB Bylaws and Mission Statement.
5. **Data Steward Responsibilities** – In addition to the general responsibilities of data stewardship described under point 1 above, each data steward shall, for all data under stewardship:
- a. Update and maintain the relevant portions of the Department's Data Inventory on DOHnet;

- b. Facilitate access to the data to the extent allowed by statutes, rules, federal requirements, Department policies, and relevant ethical principles;
- c. Create and maintain data access, security and management plans;
- d. Establish access policies and procedures that assure appropriate protection of both individual confidentiality/privacy and of the public trust under which those data are collected;
- e. Create and maintain an adequate record of data collection and management procedures and practices (data management log);
- f. Create and maintain disaster recovery and business continuity plans;
- g. Assure that data are modified only in appropriate ways;
- h. Follow state and federal legal requirements regarding release of data;
- i. Comply with the terms of applicable legal agreements and contracts;
- j. Assure that data are accessed only by authorized individuals and for authorized purposes;
- k. Comply with requirements for registration of data records with the state archivist and fulfilling functions of the records officer;
- l. Implement data sharing agreements where appropriate;
- m. Seek advice and direction from supervisor for unusual data use and data sharing situations;
- n. Assure that IRB reviews occur for uses of data that constitute human subjects research and that ethical reviews are conducted, where warranted, for non-research uses of data.

IV. Procedures for Sharing Data Among Department Programs:

Data sharing among Department's organizational units and their programs and systems is both supported and encouraged. The data requester for both one-time and ongoing sharing of data shall negotiate with the appropriate data steward. The source data steward(s) shall document the data sharing decisions in an informal data sharing agreement, by tracking the:

- A. Party, or parties, with whom data are shared;
- B. Nature/type of the data shared;
- C. Intended uses of the data;
- D. Frequency of the exchange of data.

Formal data sharing agreements are not required but may be developed by the data stewards. Documented policies, procedures, and protocols that clarify appropriate uses of data are encouraged.

V. Procedures for Release of Identifiable Health Data to Parties Outside the Department for Research:

- A. All requests for access to non-publicly available identifiable health data, made for research purposes by any outside organization or individual, shall be directed to the appropriate data steward. Requests must be in writing and must include:
 - 1. Nature/type of the data requested;
 - 2. Purposes for which the data will be used;
 - 3. Allowable uses of the data;
 - 4. Assurance that the confidentiality and security of the data will be maintained;
 - 5. Provisions for data storage, retention, and disposal.

- B. Before deciding to release individually identifiable health data, the data steward(s) shall consider the following prior to releasing the data:
1. **Need for the Requested Data** – Does there exist a compelling need or absolute necessity for the requested data; can the data be replaced with non-identifiable data; is this the minimum data to meet the need; does the need for this data justify the risk of disclosure; or can test data be used?
 2. **Use of the Data** – Will the data be used for legitimate purposes; will data use be restricted to the stated purposes?
 3. **Confidentiality/Security of the Data** – Will the data be safeguarded and protected; does there exist a potential for violation of the confidentiality of the data or actual physical theft or loss; will the data be disclosed or re-released to anyone at any time under any circumstances; and will the data be properly disposed?
- C. If uncertain if release is allowable, the data stewards shall obtain advice and direction from their immediate supervisor who will take the issue up the chain of command. If the proposed uses of the data constitute human subjects research or if statutes, rules, federal requirements, and Department policies require it, the data steward shall assure that human subjects review and approval by an appropriate IRB is obtained.
- D. Data sharing agreements are required for all external sharing of identifiable health data.
- E. The data steward will evaluate the feasibility and difficulty to produce the data and may request that an appropriate charge be paid to recover costs and applicable fees.

VI. Procedures for Release of De-identified Health Data to Parties Outside the Department:

Requests for de-identified health data by any outside organization or individual must be directed to the appropriate data steward.

- A. If the data are available publicly, the data steward shall direct the requestor to the appropriate source location.
- B. If the data are not publicly or generally available, the data steward will evaluate the feasibility and difficulty to produce the de-identified data and may request that an appropriate charge be paid to recover costs and applicable fees.

VII. Data Sharing Agreements

- A. Data sharing agreements shall be used with parties outside of the Department:
 1. When sharing identifiable health data;
 2. When sharing health data that has been de-identified by removing fewer than all of the data elements specified in the safe harbor provisions of the HIPAA privacy regulation.
- B. Data sharing agreements are not required to share data that has been de-identified by removing all or more of the data elements specified in the safe harbor provisions of the HIPAA privacy regulation, unless those data still could meet the definition of identifiable data included at the end of this document.
- C. Data sharing agreements may be required to share data among Department programs depending on the applicable statutes and regulations.
- D. Upon agreement from the data steward, or from the appropriate level of management, approval to access the data can be granted, with the following assurances given by the data requestor and recorded in a formal data sharing agreement:
 - Party, or parties with whom data will be shared;
 - Time period of the agreement;
 - Nature/type of the data requested;

- Intended uses of the data;
 - Frequency of the exchange of data;
 - Requirement that the requestor will protect completely the confidentiality of the data provided;
 - Requirement that the requestor will not disclose or release the identifiable health data without specific written permission from the Department;
 - Requirement that the requestor will report immediately the loss or theft of any identifiable data or related confidential materials to the appropriate Data Steward;
 - How the requestor will maintain the confidentiality and the security of the data;
 - A statement that the Department is either the owner or has rights to control the use and dissemination of the data;
 - Provision describing and how the data will be disposed of at the conclusion of the agreement;
 - Assurances that the requestor will obey all state and federal laws regarding the use of the data;
 - Specification of rights for audit of data use practices;
 - Provisions regarding secondary release of the data;
 - A provision that the recipient will hold the Department harmless from all liability arising from the recipient's use or disclosure of the data; and
 - Consequences of violation of the agreement.
- E. A data sharing agreement sample is attached as an appendix. Data sharing agreements may change through time and may be modified to meet specific needs.

VIII. Unresolved Issues/Policy Implementation:

Any issues remaining unresolved upon implementation of this policy or questions regarding implementation or interpretation are to be brought to the attention of the Director, Center for Health Data.

IX. Appendix:

A. Definitions:

Several terms are explained for the purpose of creating a common understanding of the issues covered by this policy.

1. **Data stewardship** – The responsibility carried out on behalf of a larger group, institution, or the public in general to safeguard, protect, and optimize the use of the data resources. Data stewardship in the Utah Department of Health relates to the data collected by an organizational unit under the authority of the Department. Protecting the Department's data resources includes, and is subject to, all the statutes and rules that pertain to the data. A data steward does not have the right to conceal or hold protected health data for personal benefit, disclose protected health data without proper authorization, or arbitrarily limit access to the data.
2. **Health data** – Any data relating to the health status of people, living or dead; all forms of data relating to health including data on the extent and nature of the illness, disability and other aspects of well being; environmental, social and other health hazards; determinants of health.
3. **Identifiable health data** – [Title 26-3-1 Definition] "Identifiable health data" means any item, collection, or grouping of health data which makes the individual supplying it or described in it identifiable.

With regard to individuals, the term means any item, collection or grouping of data which contains the name of the individual or any identifying number, symbol, other identifying characteristics, or any unique grouping of data, which, when combined with other available data, makes the individual recognizable. With regard to organizations that have received an assurance of non-disclosure from the Department, the term means, any item, collection or grouping of data, which makes the organization as recognizable as if a name had been affixed. Identifiable health data encompasses health data that identifies individuals by name, unique identifier, or other identifying characteristics. The definition also encompasses health data identifying organizations that have received an assurance of non-disclosure by the Department.

4. **Disclosure** – [Title 26-3-1 Definition] "Disclosure" or "disclose" means the communication of health data to any individual or organization outside the department.
5. **Institutional Review Board (IRB)** – An official Department body whose mission is to review for approval research projects involving human subjects. Certain statutes and rules define bona fide research approved by an IRB as one criterion for release of identifiable health data. Thus, IRB review and approval is required for certain uses of health data.

B. Data Sharing Agreement - Sample

Appendix 2: Intra-Agency CHARM Data Sharing Agreement

INTRA-AGENCY CHARM DATA SHARING AGREEMENT VITAL RECORDS BIRTH & DEATH CERTIFICATE DATA

Utah Department of Health
Child Health Advanced Records Management system (CHARM)

Data Provider:

Division/Office: Center for Health Data
Bureau/Program: Office of Vital Records and Statistics
Data Steward: Barry Nangle
Address: Cannon Building, 1st floor
Phone: 538-6907

Data Requestors:

Division/Office:	<u>Bureau of Vital Records, Statistics, and USIIS</u>
Bureau/Program:	<u>USIIS</u>
Manager/Director	_____
Address	_____
Phone	_____

Division/Office:	<u>Early Intervention</u>
Bureau/Program:	_____
Manager/Director	_____
Address	_____
Phone	_____

Division/Office:	<u>Newborn Screening</u>
Bureau/Program:	_____
Manager/Director	_____
Address	_____
Phone	_____

Division/Office:	<u>Hearing Speech and Vision Screening</u>
Bureau/Program:	_____
Manager/Director	_____
Address	_____
Phone	_____

Division/Office:	<u>Birth Defect Network</u>
Bureau/Program:	_____
Manager/Director	_____
Address	_____
Phone	_____

I. PURPOSE

The Utah Department of Health (Department) has many programs that conduct traditional public health activities such as newborn hearing and metabolic screening, early intervention follow-up for at risk children, immunization documentation, birth defects monitoring, and many other population-based preventive and direct health services. Historically, the Department's information systems have been very de-centralized, resulting in 1) duplicate demographic information across programs, and 2) non-existent, or inefficient mechanisms for sharing pertinent data between programs. The CHARM project is a

collaborative effort to share valuable data between Department programs. It also allows each program to maintain their own program data and control what data is shared and with whom.

Authorized Use: Authorized uses for accessing vital records data via CHARM include:

1. Improve follow-up efforts by providing an accurate source of biographical and demographic information, such as names and addresses. May contact individuals for public health follow-up purposes.
2. Streamline registration and monitoring processes by providing bio-demo data to programs, reducing double data entry for staff, and duplicate forms for clients.
3. To identify adoption and death status so families are not inappropriately contacted.
4. Can be used for public health surveys and other research purposes under the administrative rule, with written authorization of the state registrar.
5. May use health risk and medical information as specified in the Child Health Profile.
6. May use CHARM for official state purposes.
7. All CHARM users need to document and share with the Bureau of Vital Records and Statistics how they intend to use vital records data in section III of this document. Utilizing vital records data for any other purpose will need to be communicated with the Bureau of Vital Records and approved by the state registrar.

II. JUSTIFICATION

Data are essential to the mission and purpose of the Department. Data collected by organizational units or individuals within the Department are collected under the authority of the Department and the stewardship and use of those data are ultimately the responsibility of the Department. The missions and purposes of organizational units within the Department overlap in many instances and sharing data will often help the Department to accomplish its mission.

Vital Records has a long history of sharing data. Vital Records have special exemption status in HIPAA (Health Insurance Portability and Accountability Act) with a few constraints on births and deaths. Vital Records data can be used for all official purposes including the federal, state, and local government levels. Barry Nangle, Director of Vital Records has authority to review and approve data sharing requests. There are no provisions for sharing information internationally or with Native American tribes.

Privacy and Confidentiality: Only Department employees who have read, understood, and signed the Confidentiality Pledge (ATTACHMENT A), will have access to CHARM. These employees will only use this information under the conditions of the Confidentiality Pledge.

Supportive Legislation for Data Sharing: It is evident that the CHARM programs that use Vital Records data have a direct, tangible, and legitimate purpose for having access. The purpose is directly related to public health activities, follow-up for high-risk children, and a more efficient mechanism to deliver public health services. Utah Code -- Title 26 -- Chapter 02 -- Utah Vital Statistics Act: (ATTACHMENT B 26-2-22 Inspection of Vital Records) supports the use of sharing vital records for traditional public health activities as long as the state registrar approves and a direct, tangible, and legitimate interest is demonstrated by the user. This legislation states that:

“The vital records shall be open to inspection, but only in compliance with the provisions of this chapter, department rules, and Section 78-30-18. It is unlawful for any state or local officer or employee to disclose data contained in vital records contrary to this chapter or department rule.” It goes on to also state that “ A custodian of vital records may permit inspection of a vital record or issue a certified copy of a record or a part of it when the custodian is satisfied the applicant has demonstrated a direct, tangible, and legitimate interest.”

A direct, tangible, and legitimate interest in a vital record is present only if:

- (a) the request is from the subject, a member of the subject's immediate family, the guardian of the subject, or a designated legal representative;
- (b) the request involves a personal or property right of the subject of the record;

- (c) the request is for official purposes of a state, local, or federal governmental agency;*
- (d) the request is for a statistical or medical research program and prior consent has been obtained from the state registrar;*
- or*
- (e) the request is a certified copy of an order of a court of record specifying the record to be examined or copied...*”sharing of vital records for the purpose of traditional public health activities. (attachment 2)

Adoptions: “...(c) except as provided in Title 78, Chapter 30, Adoption, a parent, or the immediate family member of a parent, who does not have legal or physical custody of or visitation or parent-time rights for a child because of the termination of parental rights pursuant to Title 78, Chapter 3a, Juvenile Courts, or by virtue of consenting to or relinquishing a child for adoption pursuant to Title 78, Chapter 30, Adoption, may not be considered as having a direct, tangible, and legitimate interest;...”

III. DATA USE INTENTIONS

The USIIS program intends to utilize vital records information for the following purposes:

1. (list defined by the Program)

The Newborn Screening Program intends to utilize vital records data for the following purposes:

1. (list defined by the Program)

The Early Intervention Program intends to utilize vital records data for the following purposes:

1. (list defined by the Program)

The Hearing Screening and Vision Screening Program intends to utilize vital records data for the following purposes:

1. (list defined by the Program)

The Birth Defects Network Program intends to utilize vital records data for the following purposes:

1. (list defined by the Program)

*Note: This section can be amended as necessary. All amended updates shall be shared with all CHARM programs.

IV. DESCRIPTION OF DATA

Birth and Death Certificate (Vital Records)

Major Role of Vital Records

1. Civil registration - Providing information about facts of birth for legal purposes such as documenting citizenship. Anyone born in U.S. is a citizen. Death certificates have a legal function.
2. Public health statistical function – Vital Records are used for surveillance and monitoring of public health. These data are also used to assist public health agencies in providing services.

Vital records birth and death records contain person (names), locator (addresses), demographics (geography, race, Hispanic Origin, education, marital status, etc), administrative, and health and medical information about individuals. The data elements to be shared with CHARM programs, as well as the conditions under which they are to be shared are illustrated in ATTACHMENT C

IV. METHOD OF ACCESS OR TRANSFER

CHARM is a secure, distributed middleware solution that aims to integrate autonomous health-care information systems. Although CHARM will appear as a central repository of Child Health Profiles to any

participating program, it will not store any program-specific data. Instead, it will only store some limited demographic information on each child (just enough to be able to identify duplicate persons) and will obtain all program-specific data in real-time from the participating programs as needed. This will allow the individual health-care programs to retain control over their own data. Also, they will be free to enhance and evolve their own information systems as they see fit.

V. LOCATION OF DATA AND CUSTODIAL RESPONSIBILITY

Each program integrated into CHARM is responsible for their respective data sets in terms of secure storage, maintenance of security, and the prevention of unauthorized use. The CHARM administrator is responsible for assuring program security specifications are met in the CHARM application.

Vital Records birth and death registration data are stored (...to be developed)

VI. CONFIDENTIALITY

The user agrees to establish appropriate administrative, technical, and physical safeguards to protect the confidentiality of the data and to prevent unauthorized use or access to it. This agreement represents and warrants further that, except as specified in an attachment or except as authorized in writing, that the data covered by this agreement shall not be disclosed, released, revealed, showed, sold, rented, leased, loaned or otherwise have access granted to any person. Access to the data covered by this agreement shall be limited to the minimum number of individuals necessary to achieve the purpose state in this agreement and to those individuals on a need-to-know basis only. Specific un-authorized uses for CHARM data are 1) using individually identifiable data to contact an individual for purposes other than stated in section I. PURPOSE, and 2) sharing CHARM information with insurance companies, HMOs, or other outside agencies.

The safeguards shall provide a level and scope of security that is not less than the level and scope of security established by the Data Steward or required by federal or state statute/rule/regulation. It is strongly suggested that the guidelines presented in the Model State Vital Statistics Act be applied (available from the U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Hyattsville, Maryland (DHHS) Publication No. (PHS) 95-11 1 5.)

VII. SIGNATURES

ATTACHMENT A

CONFIDENTIALITY PLEDGE

UTAH HEALTH DATA COMMITTEE
UTAH DEPARTMENT OF HEALTH
OFFICE OF HEALTH CARE STATISTICS

Confidential information, or data, is defined as “any information where the individual described is named or otherwise identifiable”. As a condition for my access to the facilities and confidential data of the Utah Health Data Committee (HDC), I agree to uphold the confidentiality of the data in accordance with the following requirements:

I will avoid any action that will provide confidential information to unauthorized individuals or agencies.

- I. I will not scan or review any HDC records or files to which I do not have specific authorization.
- II. I will not make copies of any confidential HDC records, except as specifically authorized.
- III. I will not remove any confidential information from committee meetings or from the Office of Health Care Statistics, except as specifically authorized.

- IV. All confidential data in my possession will be maintained in a safe manner which restricts unauthorized individuals from access.
- V. I will not discuss information that might lead to identification of individuals described in the HDC's health data files with any unauthorized person.
- VI. I will limit my use of confidential HDC data to the purposes for which I have been specifically authorized.
- VII. I will not give my password(s) or file access codes to any unauthorized person, and upon termination will arrange for appropriate disposition of these codes and of all confidential data in my possession.
- VIII. If I become aware of any unauthorized access to, or divulgence of confidential HDC data by someone else, I will report it immediately to the Director of the Office of Health Care Statistics. I understand that failure to report violations of confidentiality by others is just as serious as my own violation and my subject me to legal prosecution.

I understand that if I fail to keep my pledge of confidentiality I will be denied access to the facilities and data of the HDC, and I may be subject to legal penalties. Any use,, release, or publication of health care data contrary to the provisions stated are class A misdemeanors, and may result in civil liability (Chapter 33a, Title 26, Section 100, Utah Code Annotated). If I am an employee, this may be grounds for immediate dismissal.

I have read the above confidentiality pledge; it has been explained to me; and questions concerning it were answered prior to my signing.

Date:_____ Name:_____ (Print)

(Signature)

(Committee, Title or Position)

Health Data Committee:_____ Date:_____

Start Date:_____ Ending Date:_____

ATTACHMENT B

UTAH CODE 26-2-22 of the Utah Vital Statistics Act:
(http://www.le.state.ut.us/~code/TITLE26/htm/26_02023.htm)

Inspection of vital records.

(1) (a) The vital records shall be open to inspection, but only in compliance with the provisions of this chapter, department rules, and Section 78-30-18. It is unlawful for any state or local officer or employee to disclose data contained in vital records contrary to this chapter or department rule.

(b) A custodian of vital records may permit inspection of a vital record or issue a certified copy of a record or a part of it when the custodian is satisfied the applicant has demonstrated a direct, tangible, and legitimate interest.

(2) A direct, tangible, and legitimate interest in a vital record is present only if:

(a) the request is from the subject, a member of the subject's immediate family, the guardian of the subject, or a designated legal representative;

- (b) the request involves a personal or property right of the subject of the record;
- (c) the request is for official purposes of a state, local, or federal governmental agency;
- (d) the request is for a statistical or medical research program and prior consent has been obtained from the state registrar; or
- (e) the request is a certified copy of an order of a court of record specifying the record to be examined or copied.

(3) For purposes of Subsection (2):

- (a) "immediate family member" means a spouse, child, parent, sibling, grandparent, or grandchild;
- (b) a designated legal representative means an attorney, physician, funeral director, genealogist, or other agent of the subject or the subject's immediate family who has been delegated the authority to access vital records;
- (c) except as provided in Title 78, Chapter 30, Adoption, a parent, or the immediate family member of a parent, who does not have legal or physical custody of or visitation or parent-time rights for a child because of the termination of parental rights pursuant to Title 78, Chapter 3a, Juvenile Courts, or by virtue of consenting to or relinquishing a child for adoption pursuant to Title 78, Chapter 30, Adoption, may not be considered as having a direct, tangible, and legitimate interest; and
- (d) a commercial firm or agency requesting names, addresses, or similar information may not be considered as having a direct, tangible, and legitimate interest.

(4) Upon payment of a fee established in accordance with Section 63-38-3.2, the following records shall be available to the public:

- (a) except as provided in Subsection 26-2-10(4)(b), a birth record, excluding confidential information collected for medical and health use, if 100 years or more have passed since the date of birth;
- (b) a death record if 50 years or more have passed since the date of death; and
- (c) a vital record not subject to Subsection (4)(a) or (b) if 75 years or more have passed since the date of the event upon which the record is based.

Amended by Chapter 255, 2001 General Session

ATTACHMENT C: CONDITIONS FOR USE

Birth Records Data Use Conditions for CHARM Programs

Data Entity and Elements	Conditions for Use
PERSON	
First name	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes.
Middle name or initial	
Last name	
Suffix	
Birth Date	
Birth certificate number	
Birth record number	
Maiden name (mom only)	
LOCATOR	
Resident address (mom and infant only)	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes.
Mailing address (mom and infant only)	
Survey address (mom and infant only)	
	May use for public health surveys if approved in writing by state registrar.
PERSON ROLE	
Infant, mom, and dad	May be used by all CHARM programs. May only be used for official programmatic purposes
DEMOGRAPHIC	
Race (mother, infant, father)	May be used by all CHARM programs. May only be used for official programmatic purposes. May not be used to pass judgment on a client, or to discriminate in allocation of services.
Hispanic Y/N (Mother, infant, father)	
Hispanic Type (Mother, infant, father)	
Education Code (Mother, father)	
State of birth (Mother, infant, father)	
Age (Mother, father, infant)	
Marital status (mother only)	May be used by all CHARM programs. May only be used for official programmatic purposes. May not be used to discriminate. Only to be used for follow-up status to determine household structure and make decisions about contacting a father.

Birth Records Data Use Conditions for CHARM Programs (continued)

Data Entity and Elements	Conditions for Use
SCREEN & FOLLOWUP	
High Risk Flag	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes.
Immunization Registry opt out/enrollment	
Hearing loss detected	
HepB given	
HepB date	
Newborn screening number	
High risk county	
Low birth weight status	
Abnormal conditions (infant)	
Congenital anomalies (infant)	
Hemoglobinopathy flag (mom)	
Premature status	
FLAGS	
Adoption status	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes. May not be shared with, or used to contact any non-custodial parent or anyone other than the custodial parent.
Deceased flag	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes.
Date of death	
PREGANCY (Needs infant and mom)	
Prenatal care status (early, adequate, etc)	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes. If these data are to be used for any outreach activities, it must be reviewed and approved by the BVR and included as an amendment to section III of this document.
Adequate weight gain during pregnancy	
Previous live births	
Previous child deaths	
Antepartum procedures code	
Alcohol risk flag	
Tobacco risk flag	
BIRTH EVENT (needs infant and mom)	
Birth place type	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes. If these data are to be used for any outreach activities, it must be reviewed and approved by the BVR and included as an amendment to section III of this document.
Delivery method	
Delivery complications code	
Facility type	
Birth attendant type	
Certifier type	
Certification date	
Infant transfer Y/N	
Mom transfer Y/N	
Transfer facility	
Transfer state	
Data Entity and Elements	Conditions for Use
CHILD MEDICAL	
Birth weight grams	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes. If these data are to be used for any outreach activities, it must be reviewed and approved by the
Plurality	
Gestational age	
Apgar Scores (1 min and 5 min)	
Congenital anomalies code	

Abnormal conditions of infant codes	BVR and included as an amendment to section III of this document.
MOM MEDICAL	
Medical risk codes	May be used by all CHARM programs under the conditions of this data sharing agreement. May only be used for official programmatic purposes. If these data are to be used for any outreach activities, it must be reviewed and approved by the BVR and included as an amendment to section III of this document.